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# DISABLED AUTONOMY

KATHERINE L. MOORE, J.D.\*

Disability law is still undertheorized.<sup>1</sup> In 2007, Ruth Colker wrote that disability law was undertheorized because it conflated “separate” with “unequal,” and because disability was largely ignored or poorly understood within theories of justice.<sup>2</sup> The solution for Colker was to attach the anti-subordination perspective, which was developed to apply to race and sex, directly to disability.<sup>3</sup> This Article argues that this transportation from the race and sex contexts was a partial solution, but is not sufficient to give full substance to disability law theory.

Concepts from critical race theory and feminist jurisprudence have long been simply transported into the disability context, acting as an imperfect facsimile. The primary purpose of those concepts was to describe, analyze, and remedy problems primarily related to race and gender, not disability. While disability law has benefitted to some extent from inclusion in these legal theories, many of the unique features and complexities of disability law have been left on the table. This Article explores those complexities. Autonomy, usually thought of as an uncomplicated social good for other groups, is challenged in disability theory by two competing values. The value of anti-subordination is critical because it seeks to address, and redress, discrimination, stigma, and stereotyping. An anti-subordination perspective gives a voice and supplies resources to people with disabilities, and will counsel against choices that support stigma and stereotyping. An anti-subordination perspective might seek to limit a right to physician-assisted suicide, for example, because of concerns about exploitation and the messaging that disabled lives are not worth living. This runs counter to an autonomy-focused perspective, which would support the choice to end one’s life in the end stages of a terminal disease.

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\* Associate Professor, Seton Hall University School of Law. I thank those who commented on this and earlier versions of this Article, including Valarie Blake, Mary Crossley, Elizabeth Pendo, Alice Ristroph, William Moon, and my colleagues at Seton Hall University School of Law. I also wish to thank the participants in the AALS Section on Law, Medicine, & Health Care’s Works-In-Progress Session and the NYU Lawyering Scholarship Colloquium, for helpful comments during the preparation of this Article.

1. Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415 (2007).

2. *Id.*

3. Ruth Colker, *Anti-Subordination Above All: Sex, Race, and Equal Protection*, 61 N.Y.U. L. REV. 1003, 1007-09 (1986).

An anti-eliminationism perspective advocates for the preservation of, and resources for, disabled lives. This comes to mean that not only are people with disabilities valued, but their disability is valued too. Instead of seeking to end Autism, for example, an anti-elimination perspective seeks to support Autistics. However, an anti-eliminationism perspective might also support the restriction of choice, and therefore come into conflict with autonomy, where there is a choice that results in the end of a disability. An anti-elimination perspective could seek to restrict the ability to selectively terminate pregnancies when a disability is found, for example. Anti-eliminationism inherently challenges the notion that getting rid of disability is a good thing.

Parts I, II, and III of this Article describe the values of autonomy, anti-subordination, and anti-eliminationism in the disability context, and argue that these values are *each* critical components of disability law and theory. Part IV of this article provides an overview of some real-world examples where these values come into immediate conflict.

#### A NOTE ON LANGUAGE

The term ‘disability’ itself exemplifies some of the tensions described in this piece. It is both a big-tent platform and a narrow descriptor. In this article, the term ‘disability’ is used fluidly. The legal definition under the Americans with Disabilities Act<sup>4</sup> is different from that used by the Social Security Administration,<sup>5</sup> and from the United Nations<sup>6</sup> definition; there are assuredly more, including those that provide more precision and description.<sup>7</sup>

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4. “A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.” Americans With Disabilities Act of 1990, 42 U.S.C. § 12102(1) (1990).

5. SOC. SEC. ADMIN., DISABILITY EVALUATION UNDER SO. SEC., <https://www.ssa.gov/disability/professionals/bluebook/general-info.htm>. A person who is “not able to engage in any substantial gainful activity (SGA) because of a medically-determinable physical or mental impairment(s): That is expected to result in death, or that has lasted or is expected to last for a continuous period of at least 12 months.” *Id.*

6. “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” UNITED NATIONS, *The UN Convention on Rights of Persons with Disabilities, Article 1 - Purpose* (2012), <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>.

7. The CDC identifies disabilities that affect a person’s “Vision, Movement, Thinking, Remembering, Learning, Communicating, Hearing, Mental Health, and Social Relationships,” CENTERS FOR DISEASE CONTROL AND PREVENTION, *Disability and Healthy Overview* (last visited Aug. 1 2017) [www.cdc.gov/ncbddd/disabilityandhealth/disability.html](http://www.cdc.gov/ncbddd/disabilityandhealth/disability.html); *See also* The World Health Organization identifies three dimensions to disability: “1. Impairment in a person’s body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss. 2. Activity limitation, such as difficulty seeing, hearing, walking, or problem solving. 3. Participation restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining

Furthermore, there are language-reclaiming movements within the disability community similar to in other social justice movements. For example, the use of the word ‘crip’ is similar to that of ‘queer’ in terms of self-definitional linguistics.<sup>8</sup> The term ‘crip,’ as used by some, is intentionally an inclusive term, “representing all disabilities: people with vastly divergent physical and psychological differences.”<sup>9</sup> On the other hand, ‘people-first’ language (‘person with a disability’) is frequently favored,<sup>10</sup> while others argue that it unnecessarily “separates disability from the person”<sup>11</sup> (who therefore advocate the term ‘disabled person’). Many Autistics state that they prefer to be called Autistic rather than ‘person with Autism’.<sup>12</sup> Furthermore, some people who are categorized as disabled by society and the law do not self-identify as such: many Deaf people advance the notion that they are not disabled, but merely possess a trait in common with each other.<sup>13</sup>

Throughout, this piece attempts to utilize non-ableist language. Any missteps are the author’s own.

#### I. THE VALUE OF AUTONOMY

Autonomy, independence, and freedom of mind and body are centrally important to people with disabilities. The traditional philosophical concept of autonomy is that it can be framed as ‘self-ownership’. If you ‘own’ your life, the choices you make might be tied intimately to your sense of self.

People with disabilities may experience autonomy and choice – and therefore their sense of self – differently than non-disabled people. It is of unique concern to people whose autonomy is often taken away. Furthermore, the Kantian emphasis on rationality can also be used a weapon to strip certain individuals of their own autonomy.

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health care and preventive services.” WORLD HEALTH ORG., *International Classification of Functioning, Disability and Health* (ICF) (2001), [www.who.int/classifications/icf/en](http://www.who.int/classifications/icf/en).

8. See, e.g., ROBERT MCGRUE, *CRIP THEORY: CULTURAL SIGNS OF QUEERNESS AND DISABILITY* (2006).

9. JULIE WILLIAMS, WRIGHT STATE UNIVERSITY, *Crip Theory*, [www.wright.edu/event/sex-disability-conference/crip-theory](http://www.wright.edu/event/sex-disability-conference/crip-theory).

10. See Kathie Snow, Examples of People First Language, <https://1.cdn.edl.io/AUiNZe8nGx3v99ISy0wI09mCC6OQDKyj0TUusR3qiD4TJD7n.pdf> (giving examples of how to use people-first language and phrases instead of disability-first language).

11. JULIE WILLIAMS, *supra* note 9.

12. See for example: “I would appreciate it, if I end up in your article, if you describe me as ‘an autistic’ or ‘an autistic person,’ versus the ‘person with,’” Ms. Dawson wrote in an e-mail message. ‘Just like you would feel odd if people said you were a ‘person with femaleness.’” Amy Harmon, *How About Not ‘Curing’ Us, Some Autistics Are Pleading*, N.Y. TIMES (Dec. 20, 2004).

13. See Megan A. Jones, *Deafness as Culture: A Psychosocial Perspective*, 22(2) DISABILITY STUDIES QUARTERLY 51, 51 (2002) (describing the view among “proponents of deafness as a culture” who have “asserted that deafness is not a pathology and therefore does not need to be ‘fixed.’”)

*A. Autonomy as Self-Ownership*

Autonomy is generally seen as a social good, when it doesn't infringe on others.<sup>14</sup> Moreover, it is frequently cited as an American value,<sup>15</sup> described as a "central value underlying the First Amendment's commitment to free expression."<sup>16</sup> Gerald Dworkin for example defines autonomy as "the capacity to accept or attempt to change [preferences, desires and wishes] in light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are."<sup>17</sup> So when people exercise autonomy, they don't merely break free of restraint or control; they take ownership of their choices and their lives.<sup>18</sup> Setting the stage for any discussion of the deeper nuances of the human drive for autonomy is not a simple proposition. The desire to hold ownership over one's own life is for some people rooted in religion, while perhaps simultaneously constrained by it;<sup>19</sup> for some natural law dictates such<sup>20</sup>; and for others, freedom and autonomy must go hand in hand.<sup>21</sup> Kant writes of the rational will as an autonomous expression of our humanity, for when we make moral choices by exercising our autonomy, we express our will, and thus we are human.<sup>22</sup>

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14. See CHARLES TAYLOR, *SOURCES OF THE SELF THE MAKING OF MODERN IDENTITY* (1989) (discussing the origin of the "modern self"); Robert A. Burt, *Self-Determination and the Wrongfulness of Death*, 2 J. HEALTH CARE L. & POL'Y 177 (1999).

15. Richard H. Fallon Jr., *Two Senses of Autonomy*, 46 STAN. L. REV. 875 (1994).

16. *Id.* at 875.

17. GERALD DWORGIN, *THE THEORY AND PRACTICE OF AUTONOMY* 20 (1988).

18. *Id.*

19. See Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549 (1997) (arguing for a legal scheme that would respect a family's religious beliefs when making treatment decisions for incapacitated patients).

20. Taylor charts this development in *Sources of the Self* (note 14 *supra*); John Locke's labor theory of property posits that "every man has a Property in his own Person" and therefore their labor. JOHN LOCKE, *TWO TREATISES ON GOVERNMENT, SECOND TREATISE*, § 27, 287-88 (Peter Laslett ed., 2d ed., Cambridge Univ. Press 1967) (1690). Notable critics of this conception include Oscar Wilde, who noted that it "harmed individualism, and obscured it, by confusing a man with what he possesses." OSCAR WILDE, *THE SOUL OF MAN UNDER SOCIALISM* 13 (The Floating Press 2009) (1891). The question of how and where to draw the property lines when discussing the ownership of oneself and one's life do have bearing on disability law, including some of the areas discussed herein. For example, the right to commit suicide is discussed *infra*, with a distinction drawn between when society chooses to focus on suicide prevention and when the choice to die is instead accepted or even promoted. Outside the scope of this Article, but relevant to the discussion, are the right to hand over decision-making power regarding one's health choices, the extent to which the Genetic Information Nondiscrimination Act (GINA) affects property rights to genetic testing results, and the use of genetic testing information in disability insurance. See Brandon Keim, *Genetic Protections Skimp on Privacy, Says Gene Tester*, WIRED, May 23, 2008, <https://www.wired.com/2008/05/genetic-protect/>.

21. See JEAN-JACQUES ROUSSEAU, *THE SOCIAL CONTRACT* (1762).

22. Immanuel Kant, *THE CRITIQUE OF PURE REASON* (1781) (writing on freedom as self-determination and arguing that individual freedom is achieved through participation in the political

A main concern then emerges is the following: what meaning does one's life have, if internal decision-making is co-opted in some way? When choices are removed and when options are limited, our life's meaning and purpose may be stunted. Autonomy as a life-affirming value, in that it promotes the individual self-determination and expression of will that defines our humanity in some ways. Simultaneously, limiting the autonomy of another individual diminishes that person's humanity by disallowing their free expression of will.

The limits on individual autonomy traditionally arose from social, community, and religious pressures in order to avoid taking action.<sup>23</sup> This is because of the perceived potential harm it may cause to oneself or others.<sup>24</sup> There may be areas where we may "do just as we please", there are areas where perhaps we "ought" to do something, and there are some areas where we may not do anything at all.<sup>25</sup> Beyond personal preference, we *are* limited in what we can do and what choices we make.<sup>26</sup>

But there are other potential limits on autonomy, and this Article will investigate whether the values discussed below of anti-subordination and anti-eliminationism will rise to a level that justifies that limitation. Going forward, this Article will refer to autonomy primarily in the 'ownership of one's life' sense, which has implications for one's life choices,<sup>27</sup> and, additionally, by extension the idea of 'ownership' over one's choices in reproduction and as to one's children.<sup>28</sup> Autonomy's cousin, self-reliance, will also be discussed as it relates to self-definition and disability.

### *B. Autonomy as a Central Concern of Disability*

Autonomy is of particular concern to people with disabilities.<sup>29</sup> Facing a society that limits the ability to participate in employment, activities, social and civic life, the "major life activities" referenced by the Americans with Disabilities Act<sup>30</sup> as well as the minor life activities of everyday living, people with disabilities are perhaps uniquely positioned to articulate the human drive

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process); *See also* Paul Guyer, KANT ON FREEDOM, LAW AND HAPPINESS 13 (Brown University Press 2000) (arguing for the intrinsic value of freedom of choice).

23. *See* Lawrence C. Becker, *Crimes Against Autonomy: Gerald Dworkin On The Enforcement of Morality*, 40 WM. & MARY L. REV 959 (discussing criminal sanctions designed to limit autonomy).

24. *See id.*

25. *Id.* at 960.

26. *Id.*

27. *See* discussion of Sexual Consent and Physician Assisted Suicide, *infra* Section IV. C.

28. *See* discussion of Prenatal Testing and Anti-Autism rhetoric, *infra* Section IV. E.

29. *See* DISABILITY RIGHTS CALIFORNIA, PRINCIPLES: PERSONAL AUTONOMY, <http://www.disabilityrightsca.org/legislature/Principles/102401.htm> (last updated Sept. 16, 2017) (stating that "[a]ll people, including children, have the right to maintain personhood, bodily integrity, and personal autonomy. They also have the right to the services and supports they need to grow, develop naturally, and to live fully-integrated lives of quality in their own homes and communities.").

30. Americans With Disabilities Act of 1990, 42 U.S.C. § 12101(b) (hereinafter ADA).

towards autonomy and away from restraint. This is especially relevant in cases where an individual is beholden to someone else's decision-making about their own life.

The struggle for autonomy for people with disabilities has been a hard-fought road. It encompasses a history laden with the abuse of vulnerable populations in profound ways.<sup>31</sup> Accessibility and inclusion within society have been historically unavailable to people with disabilities, and abuse, neglect, and segregation from mainstream society<sup>32</sup> have been commonplace.

Autonomy over decision-making and a sense of self-ownership are key to ensuring that people with disabilities remain present, integrated, and seen in the public sphere. People with disabilities must be recognized as valuable to society, both as Kantian "ends in themselves"<sup>33</sup> and as distinct contributors to diversity of thought and experience.<sup>34</sup> Autonomy is integral to this conception. As described *supra*, autonomy is an expression of intrinsic humanity.<sup>35</sup> This manifestation of choice and will is what makes us human.

Moreover, the history of autonomous self-determination for vulnerable groups is a history of oppression.<sup>36</sup> Robert Burt traced this history when he wrote that, in American history:

[E]ach act of liberation carried out in the name of the self-determination ideal - was accompanied by a powerful reaction, a powerful oppression directed against some other, more socially vulnerable group. This attack was, moreover, specifically directed against the imagined capacity, the right, of the members of this group to see themselves and be seen as "self-determining selves." At the very moment, that is, that this capacity, this right, was awarded to some people, it was withheld from - and even diminished from its previous, though tentative, recognition in - other people.<sup>37</sup>

Burt argues that the social liberations of one group have been followed by *increased* oppressions against other groups, which falls at the feet of self-

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31. See Colker, *supra* note 1.

32. See DISABILITY RIGHTS CALIFORNIA, WHAT WE DO, <https://www.disabilityrightscalifornia.org/what-we-do/strategic-plan> (exemplifying organizational goals, initiative, and objectives of Disability Rights California to remediate past accessibility and inclusion issues).

33. See Immanuel Kant, GROUNDWORK OF THE METAPHYSICS OF MORALS 41 (Cambridge U. Press 2012) (1785) ("So act that you use humanity, in your own person as well as in the person of any other, but always at the same time as an end, never merely as a means."). *Id.*

34. See David Bernstein, *Some Disabilities Are Actually Quite Good For Society*, GOOD April 27, 2013; See also Elizabeth Barnes, *Valuing Disability, Causing Disability* 125 ETHICS 88 (2014) (proposing the "mere difference" view of disability, arguing against value judgements related to disability as contrasted with non-disability, and that people with disabilities would be just as well off as the non-disabled in a just society).

35. *Supra* notes 20–23 and accompanying text.

36. See Burt, *supra* note 14.

37. *Id.* at 197.

determination.<sup>38</sup> Burt writes that the self-determination ideal's dark side is an "inherent inclination of this ideal toward harmful inflictions on socially vulnerable people, that is, a 'slippery slope' toward injustice and oppression."<sup>39</sup> This 'dark side' of autonomy is of concern to people with disabilities because it reveals the conflict that occurs when autonomy clashes with other values and principles, specifically those values that promote the protection or empowerment of vulnerable groups. Finally, as Carlos Ball argues, the value of autonomy places a particular responsibility on society to help people with disabilities exercise that autonomy.<sup>40</sup> "The emphasis that the disability rights movement places on deinstitutionalization and independent living shows the crucial role that notions of autonomy play in allowing the disabled to lead good and fulfilling lives."<sup>41</sup> Therefore, Ball argues, justice demands "a requirement that needs be met in a way that provides the individual with as much personal autonomy as is possible under the circumstances."<sup>42</sup> Autonomy must essentially be maximized.<sup>43</sup>

### C. The 'Rational Mind' as a Tool to Remove Autonomy

The final piece of the autonomy puzzle is the use of the 'rational mind' as a tool, or weapon, to remove autonomy from people with disabilities. Here, there are two concerns. First, people with certain mental illnesses, Intellectual Disability, developmental disabilities, or cognitive functioning limitations may not *actually* be able to make rational decisions under certain criteria, either during particular times or throughout their lives. But second, there is a long history of discrimination and abuse that has been justified by the *assumption* that people with these disabilities are fundamentally incapable of rational thought, an assumption that is based on stigma, fear, and ignorance. If autonomy is centered on rationality, people with disabilities will struggle to hold on to their own power of choice.

As discussed *supra*, Kant writes of the rational will as an autonomous expression of our humanity; when we make moral choices by exercising our autonomy, we express our will, and thus we are human.<sup>44</sup> What, then, when we cannot express a rational will? The ability to express rational will can be inhibited

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38. *Id.* at 201.

39. *Id.* at 201.

40. Carlos A. Ball, *Autonomy, Justice, And Disability*, 47 UCLA L. REV. 599, 633 (2000).

41. *Id.*

42. *Id.* . Ball writes generally that "[t]he concept of autonomy places on society a moral obligation to assist individuals with disabilities when their basic human functional capabilities are impaired." *Id.* at 599.

43. *See id.*

44. Immanuel Kant, *THE CRITIQUE OF PURE REASON* (1781); *See also* Paul Guyer, *KANT ON FREEDOM, LAW AND HAPPINESS* (Brown University Press 2000) (arguing for the intrinsic value of freedom of choice).

by mental illness.<sup>45</sup> The ability to communicate rational will might be limited by constraints on the ability to communicate.<sup>46</sup> Intellectual Disability, a developmental disability, or cognitive functioning limitation might also interfere here, and in particular might interfere with communication of that will.<sup>47</sup> In this case, the law provides a remedy of sorts in guardianship: the provision of “a legal process consisting of a court-appointed relationship between a competent adult and a person over the age of eighteen whose disability renders him/her unable to make an informed decision or at risk of doing harm to self or others due to an inability to manage his/her own affairs.”<sup>48</sup> The relationship created by guardianship might be troubled or even abusive.<sup>49</sup>

Next, the mere *assumption* that people with certain disabilities cannot make rational choices is frequently enough to limit their autonomy. Historically, a diagnosis of Intellectual Disability was considered an insurmountable barrier to achieving independence and self-sufficiency. As a result, persons with

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45. Take for example psychosis, which “is defined as the experience of loss of contact with reality, and is not part of the person’s cultural group belief system or experience.” A person experiencing psychosis has delusions or “fixed false beliefs” which “beliefs do not change or modify when the person is presented with new ideas or facts. *Types of Mental Illness*, NAT’L ALL. ON MENTAL ILLNESS, [www.namlica.org/resources/mental-illness/types-mental-illness](http://www.namlica.org/resources/mental-illness/types-mental-illness).

46. *Id.* (noting that when an individual experiences hallucinations, it can be very confusing to surrounding family, friends, and caretakers).

47. Approximately 1.2 million adults have Intellectual Disability or a developmental disability, or a condition that limits cognitive functioning. Matthew W. Brault, *U.S. Census Bureau, Americans with Disabilities: 2010 Household Economic Studies*, 1, 9 (2012), <https://www2.census.gov/library/publications/2012/demo/p70-131.pdf>. Developmental disability is an umbrella term that includes Intellectual Disability, which is characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills. ROBERT L. SCHALOCK ET AL., AM. ASS’N ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, INTELLECTUAL DISABILITY: DEFINITION, CLASSIFICATION, AND SYSTEMS OF SUPPORTS 1 (11th ed. 2010) (hereinafter “AAIDD”). The cognitive aspect of Intellectual Disability refers to reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, and learning. Adaptive functioning refers to a collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives. *Id.*

Persons with Intellectual Disability have limitations in certain adaptive behaviors that impact conceptual, social, or practical functioning. *See* AAIDD; *See also Diagnostic and Statistical Manual of Mental Disorders Intellectual Disability Fact Sheet*, AM. PSYCHIATRIC ASS’N, [https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA\\_DSM-5-Intellectual-Disability.pdf](https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM-5-Intellectual-Disability.pdf) (hereinafter “DSM-5 Fact Sheet”). Conceptual functioning relates to the ability to communicate orally, read, write, reason, learn and retain knowledge and information. *Id.* Social functioning encompasses the ability to have empathy, make social judgments, socialize, interact with others and make and retain friendships. *Id.* Practical functioning may involve the ability to engage in personal care, manage money, use transportation, conduct housekeeping activities, maintain a safe environment, use the phone and perform other activities of daily living. *See e.g. Introduction to Intellectual Disability*, THE ARC, <https://thearc.org/wp-content/uploads/forchapters/Introduction%20to%20ID.pdf>.

48. *Future Care Planning*, NAT’L ALL. ON MENTAL ILLNESS, [www.naminys.org/mental-health-support/navigating-details/future-care-planning](http://www.naminys.org/mental-health-support/navigating-details/future-care-planning).

49. Though outside the scope of this Article, the relationship between a person with a disability and a ‘guardian’ raises substantial issues of autonomy and self-direction.

intellectual disability faced involuntary institutionalization, forced sterilization and segregation from the community. In the landmark decision *Olmstead v. L.C. ex rel. Zimring*, the United States Supreme Court determined that unjustified institutional segregation of individuals with intellectual disability constituted discrimination under Title II of the Americans with Disabilities Act (ADA).<sup>50</sup> Following *Olmstead*, States were no longer allowed to put individuals with disabilities in state- run institutions if they were capable of – and consented to – being integrated into the community.<sup>51</sup> For an example of how decision-making and choice have historically been forcibly removed from people with disabilities, women with Intellectual Disability were targeted as early subjects of what would become a sweeping global eugenics movement that spanned from 1890 to the early 1940s, and decades longer in some marginalized communities.<sup>52</sup>

The purported goal of the eugenics movement was to create a “superior human stock” by eradicating the reproduction of those deemed “unfit.”<sup>53</sup> Eugenicians believed that social problems, such as so-called feeble-mindedness, poverty, and unwanted children could be alleviated by controlling social breeding.<sup>54</sup> Approximately 70,000 women and men were involuntarily sterilized in the United States during the eugenics movement.<sup>55</sup>

In 1927, the United States Supreme Court in *Buck v. Bell* sanctioned the eugenics movement by upholding a Virginia law that permitted involuntary sterilization of people with disabilities when a state institution deemed it in the best interest of the resident and society.<sup>56</sup> Justice Oliver Wendell Holmes, Jr., a fervent supporter of eugenics, wrote the opinion for the Court.<sup>57</sup> In a decisive two-page decision, he determined it was the duty of society to “prevent those who are manifestly unfit from continuing their kind,” and ended the opinion with his now infamous words: “Three generations of imbeciles are enough.”<sup>58</sup> By

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50. 42 U.S.C. § 12132 (effective July 26, 1990); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

51. *Olmstead* 527 U.S. at 597.

52. See, e.g., JAMES W. TRENT JR., *INVENTING THE FEEBLE MIND: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES, 193-194* (1994) (detailing the history of forced sterilization in the United States); Lutz Kaelber, *Eugenics/Sexual Sterilizations in North Carolina, Eugenics: Compulsory Sterilization in 50 American States*, <https://www.uvm.edu/~lkaelber/eugenics/NC/NC.html> (providing data on sterilizations in North Carolina from 1924 to 1973) (last updated Oct. 30, 2014).

53. TRENT, *supra* note 52, at 136.

54. *Id.*

55. Adam Cohen, *Fresh Air: The Supreme Court Ruling that led to 70,000 Forced Sterilizations*, NATIONAL PUBLIC RADIO (March 7, 2016), <http://www.npr.org/sections/health-shots/2016/03/07/469478098/the-supreme-court-ruling-that-led-to-70-000-forced-sterilizations>.

56. *Buck v. Bell*, 274 U.S. 200, 206 (1927).

57. *Id.* at 205.

58. *Id.* at 207.

1930, more than 30 states had passed involuntary sterilization statutes.<sup>59</sup> Although no longer regarded as defensible law, the United States Supreme Court has not yet explicitly overruled *Buck v. Bell*.<sup>60</sup>

Although *Buck v. Bell* was decided nearly 90 years ago, the biases and stereotypes that drove the eugenics movement continue to harm parents with Intellectual Disability today.<sup>61</sup> As recently as 1994, child welfare agency workers told a parent with Intellectual Disability that if she consented to sterilization she would get her children back.<sup>62</sup> The mother underwent a tubal ligation.<sup>63</sup> The child welfare agency nonetheless moved forward to recommend the termination of the mother's parental rights.<sup>64</sup> Furthermore, stigma and discrimination are an fact of life for many people with mental disabilities.<sup>65</sup> People with mental illness frequently face "poverty, homelessness and unemployment due to discrimination in the workplace and the benefits system."<sup>66</sup> Stigma and negative attitudes are so significant that they prevent people with mental illness from seeking medical treatment.<sup>67</sup> This is due to both the e prejudice and discrimination.<sup>68</sup>

Common misconceptions about mental illness yield three primary models of discrimination: "fear and exclusion: persons with severe mental illness should be feared and, therefore, be kept out of most communities;" "authoritarianism: persons with severe mental illness are irresponsible, so life decisions should be made by others;" and "benevolence: persons with severe mental illness are childlike and need to be cared for."<sup>69</sup> These misconceptions persist because prejudice is "(1) largely invisible, (2) largely socially acceptable, and (3) frequently practiced (consciously and unconsciously)."<sup>70</sup>

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59. Philip R. Reilly, *Involuntary Sterilization in the United States: A Surgical Solution*, 62 THE Q. REV. OF BIOLOGY 153 (1987).

60. *Id.*

61. *Id.*

62. *Vaughn v. Ruoff*, 253 F.3d 1124, 1127-28 (8th Cir. 2001).

63. *Id.* at 1128.

64. *Id.*

65. David Batty, *People with Mental Illness Face Widespread Discrimination*, THE GUARDIAN, (April 28, 2004), <https://www.theguardian.com/society/2004/apr/28/equality.mentalhealth>.

66. *Id.*

67. Claire Henderson et al., *Mental Illness Stigma, Help Seeking, and Public Health Programs*, 103 AM. J. PUB. HEALTH 777 (2013).

68. *See id.*; *see also* Sara Heath, *Understanding Stigma as a Mental Health Access Barrier*, PATIENT ENGAGEMENT HIT: PATIENT CARE ACCESS NEWS (June 8, 2017), <https://patientengagementhit.com/news/understanding-stigma-as-a-mental-healthcare-barrier>.

69. Patrick W. Corrigan and Amy C. Watson, *Understanding the Impact of Stigma on People with Mental Illness*, 1 WORLD PSYCHIATRY at 17 (2002).

70. Michael L. Perlin, "What's Good is Bad, What's Bad is Good, You'll Find Out When Reach the Top, You're on the Bottom": Are the Americans with Disabilities Act (and *Olmstead v. L.C.*) Anything More than "Idiot Wind?," 35 U. MICH. J.L. REFORM 235, 236 (2001).

These misconceptions and unconscious beliefs can have profoundly harmful effects.<sup>71</sup> For example, the child welfare context shows that the freedom of an individual to choose when and if to have a child is put in jeopardy for people with disabilities.<sup>72</sup> There is a longstanding “underlying belief that persons with mental disabilities should not reproduce and are inherently unable to provide proper parenting to their children.”<sup>73</sup> The disturbing history of sterilization of disabled people is the extreme outcome of these beliefs, and other troubling outcomes persist today.<sup>74</sup> Indeed, parents with serious mental illness lose custody of their children and have their parental rights terminated at disproportionately high rates despite low rates of child abuse.<sup>75</sup> However, psychotic illness “does not need to interfere with an individual’s ability to be a good parent”<sup>76</sup> given “well-timed, appropriate, and adequate education and resources.”<sup>77</sup> The loss of the right to parent serves as just one example of a tragic loss of autonomy many people with disabilities face, created by the perfect storm of stigma, bias, and fear.<sup>78</sup>

## II. THE VALUE OF ANTI-SUBORDINATION

Marginalized groups are subject to overt and covert subordination under the law and in society.<sup>79</sup> Subordination can take the form of discrimination, stigma, stereotyping, exclusion, and oppression.<sup>80</sup> The anti-subordination perspective is critically important to people with disabilities.<sup>81</sup>

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71. Susan Kerr, *The Application of the Americans with Disabilities Act to the Termination of the Parental Rights of Individuals with Mental Disabilities*, 16 J. CONTEMP. HEALTH L. & POL’Y 387 (2000).

72. *Id.*

73. *Id.* at 387-88, 403-04.

74. *Id.* at 403-04.

75. KATHERINE A. JUDGE, *Serving Children, Siblings, and Spouses: Understanding the Needs of Other Family Members*, in HELPING FAMILIES COPE WITH MENTAL ILLNESS 161, 164 (Harriet P. Lefley ed., 1994).

76. Mary V. Seeman, *Intervention to Prevent Child Custody Loss in Mothers with Schizophrenia*, 2012 SCHIZOPHRENIA RES. AND TREATMENT 1 (2012)

77. *Id.*

78. NAT’L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN, (September 27, 2012), [http://www.ncd.gov/rawmedia\\_repository/89591c1f\\_384e\\_4003\\_a7ee\\_0a14ed3e11aa.pdf](http://www.ncd.gov/rawmedia_repository/89591c1f_384e_4003_a7ee_0a14ed3e11aa.pdf) (explaining the differences that parents with disabilities are more likely to face, such as removal of their children, termination of their parental rights, discrimination is custody, difficulty in accessing assistive reproductive technology, and face barriers to adoption)

79. See generally Colker, *supra* note 1 (discussing the subordination of marginalized groups). See also Colker, *supra* note 3 (discussing how people with disabilities are impacted by subordination).

80. *Id.*

81. *Id.*

*A. The General Anti-Subordination Perspective*

Anti-subordination is the idea that groups of people should not be subordinated to others in society.<sup>82</sup> Further, society's role in historic subordination should be considered when remediating discrepancies in treatment.<sup>83</sup> Anti-subordination is distinct from anti-differentiation which supports policies that seek to treat everyone the same, but in practice disadvantage certain groups.<sup>84</sup> The anti-subordination principle articulates the need for group-specific policies and reforms to redress historic subordination.<sup>85</sup> One example of an anti-subordination based policy is affirmative action, which can seek to redress both the historical and present role of discrimination in hiring.<sup>86</sup> Due to a long history of racial discrimination, group-specific policy might be necessary to redress the current effects of that past discrimination.<sup>87</sup> In addition, the effects of present discrimination might narrow a pool of applicants, however affirmative action policies could be enacted to actively seek out group-specific candidates to address this disparity.<sup>88</sup>

In her discussion of the formation of Critical Race Theory, Kimberlé Crenshaw describes the way that subordination occurs in law school:

[t]he wholesale failure to consider the interests of underserved communities, the failure to interrogate the gaping contradictions between the formal commitment to the rule of law and the realities of racial dictatorship through much of the nation's history, the failure to reward innovative legal theories or to explore the reformist potential of legal advocacy—all these features of the pre-civil rights elite legal education might have been viewed from a position of skepticism given their collaborative role in normalizing broad scale societal stratification. That “excellence” and “merit” could be attached to legal thinking that consistently failed to take up some of the most complex legal problems in society was troubling enough during segregation's tenure, but to effortlessly reproduce these values in a post-segregation world seemed to undermine rather than enhance the claims of social progress.<sup>89</sup>

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82. Colker, *supra* note 3, at 1007.

83. *Id.* at 1007-10

84. *Id.* at 1012.

85. *Id.* at 1015.

86. *Id.* at 1047.

87. *Id.* at 1013.

88. *Id.* at 1047.

89. Kimberlé Williams Crenshaw, *20 Years of Critical Race Theory: Looking Back To Move Forward*, 43 CONN. L. REV. 1253, 1273-74 (2011).

Adding to the complexity, taking an anti-subordination perspective with respect to one group *might* come into conflict with that of another group.<sup>90</sup> Intersectional analysis generally seeks to dismantle systems of multiple oppressions, “[w]here systems of race, gender, and class domination converge.”<sup>91</sup> As Kimberlé Crenshaw notes, “identity politics” fails when “it frequently conflates or ignores intragroup differences.”<sup>92</sup> The ‘disability’ grouping exemplifies this entirely – not only is there great diversity in whom is disabled, there is also tremendous diversity in what disability *is*. Disability cuts across lines of race, gender, class, etc., but also encompasses a vast array of experiences, from physical disability to mental health conditions to neurological differences.

Therefore, within that diversity, it is perhaps inevitable that there will be competing goals. Beth Ribet identifies this as ‘disablement,’ and argues that “[t]here is, as yet, no sustained critical discourse that acknowledges the collective disablement of subordinated populations, and particularly Communities of Color, as a figurative, legal, and fully embodied reality in which it is possible to acknowledge that people are ‘disabled by White supremacy.’”<sup>93</sup> This might present a conflict because the disability-rights focus in moving away from a medical model of disability might lead to a dismissal of legitimate concerns about access to health justice.<sup>94</sup> Though not the central concern of this article, this complexity is worthy of acknowledgement and further discussion.

### *B. Anti-Subordination and Disability*

Anti-subordination is typically associated with racial and gender discrimination and oppression.<sup>95</sup> However, Ruth Colker and Samuel Bagenstos have both applied the idea of anti-subordination to people with disabilities.<sup>96</sup> As Ruth Colker explains it, “[u]nder the anti-subordination perspective, it is inappropriate for certain groups in society to have subordinated status because of their lack of power in society as a whole.”<sup>97</sup> Furthermore, integration is not

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90. Kimberlé Williams Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color* 43 STAN. L. REV. 1241, 1246 (1991).

91. *Id.* at 1246.

92. *Id.* at 1242.

93. Beth Ribet, *Surfacing Disability Through A Critical Race Theoretical Paradigm*, 2 GEO. J. L. & MOD. CRITICAL RACE PERSP. 209, 245 (2010).

94. *See id.* at 245; *see also* Chandra L. Ford & Collins O. Airhihenbuwa, *Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis*, 100(SUPPL 1) AM. J. PUBLIC HEALTH (2010) (arguing that structural racism’s influence on health outcomes are not adequately addressed, and that “health for all cannot be achieved if structural racism persists”).

95. *See e.g.*, Colker, *supra* note 3, at 1011, 1013. (arguing for the use of anti-subordination when confronted with race and sex issues, especially as it pertains to an equal protection analysis).

96. *Id.* Samuel Bagenstos, *Subordination, Stigma, and “Disability,”* 86 VA. L. REV. 397 (2000).

97. Colker, *supra* note 3, at 1007.

the only feature of promoting the dignity of people with disabilities; the value for some people of separateness must also be respected.<sup>98</sup> This includes “disability-only services and institutions that are available to those who need or desire them, while also creating safeguards to prevent some people from being inappropriately coerced into entering disability-only institutions, particularly residential institutions ...”<sup>99</sup>

Subordination is, in Samuel Bagenstos’s conception, formed from and given life by stigma against people with disabilities.<sup>100</sup> He writes that there are three “means by which society attaches systematic disadvantage to particular impairments:” 1. that people with disabilities “constitute an identifiable group of people who experience similar, systematic obstacles to participation in a range of activities in public and private life”; 2. that “those obstacles result from society’s prejudices, stereotyping and neglect”; and 3. that “the very social practices that attach systematic disadvantage to particular impairments are what create the category of people with disabilities.”<sup>101</sup> Bagenstos writes that stigma ties these three concepts together; stigma accounts for the historic exclusion of people with disabilities from public life and society, but also for the “widespread belief in the ability of modern medicine to enhance our mental and physical lives,” which means that “the ideological currents that exclude people with disabilities from our notion of the ‘norm’ stubbornly remain with us.”<sup>102</sup>

Anti-subordination expresses concerns around inclusion in public life, access to services, empowerment, and freedom from abuse; it also rejects concepts of disability as something to be pitied, as a cause that only needs charity.<sup>103</sup> Anti-subordination demands that society see people with disabilities as individuals and not only as either tragic or inspirational stories.<sup>104</sup> This perspective also captures the move from the medical model of disability to the social model, which moved the focus of ‘solving’ disability off the individual and on to the world which frequently fails to accommodate it.<sup>105</sup>

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98. Colker, *supra* note 1, at 1418.

99. *Id.* at 1423.

100. Bagenstos, *supra* note 96.

101. *Id.* at 436.

102. *Id.* at 444.

103. *See id.*

104. *Id.*

105. The difference between the ‘medical model’ and ‘social model’ of disability is essentially the foundation of disability studies – the shift from viewing disability as a problem within the disabled person to viewing it as a problem with a society that fails to accommodate that person was the crucial move. “Disability Studies . . . stands in sharp contrast to the study of disability which focuses on the person with a disability as one with medical, physiological, anatomical, psychological and functional pathologies that originate in the body or mind of the person. By contrast, Disability Studies embodies values based on viewing the person with a disability not as a victim of pathology, but as one who is limited more by social attitudes and environmental barriers than any inherent ‘defect’ or ‘deficiency’ within the person that must

However, while anti-subordination may provide solutions to some of the problems people with disabilities face, the inclusion of disability is clearly an afterthought. For example, while “a number of the founders of Critical Race Studies (CRS) have articulated a praxis and methodology acutely focused on race, and also intently conscious of intersectionality,” it is nonetheless the case that “[r]elatively few CRS authors have explicitly taken up the challenge of articulating disability in CRS scholarship.”<sup>106</sup> Indeed, Ruth Colker wrote about anti-subordination as applied to sex and race in 1986,<sup>107</sup> and only applied it to disability twenty year later.<sup>108</sup>

Beth Ribet identifies this problem and argues that disability should be brought ‘into the fold’ of critical race theory.<sup>109</sup> And, it is true that the historically “strong association between disease and deformity and racial images and ideologies” is pernicious in that it is used as “evidence of supposed gender, racial, cultural or class inferiority.”<sup>110</sup> Ribet astutely acknowledges that there is more to the intersection of race and disability than just the reinforcing or intensifying of stereotypes.<sup>111</sup>

However, disability legal studies must go even further than that. Certainly, siloed categorization is not the goal here. This Article’s quarrel is not with the idea that dissecting intersecting oppressions is worthwhile. Instead, this Article argues that anti-subordination is not *sufficient* to fully understand disability. To the extent that disability is theorized, it must be theorized alongside other oppressions, *but also on its own terms*. This is where the next section is germane – understanding the anti-eliminationist perspective.

### III. THE VALUE OF ANTI-ELIMINATIONISM

Anti-eliminationism is the perspective that society should not seek to eliminate people with disabilities.<sup>112</sup> Then, it goes one step further to assert that *disability itself* should not be eliminated. While we might have moved away from the idea that people with disabilities should be removed from society and towards

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be remedied.” Arlene S. Kanter, *The Law: Whats Disability Studies Got To Do With It Or An Introduction To Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 402, 409 (2011).

106. Ribet, *supra* note 93, at 209.

107. See Colker, *supra* note 3.

108. Colker, *supra* note 1, at 1418.

109. See Ribet, *supra* note 93, at 245.

110. *Id.* at 213.

111. *Id.* at 210.

112. As used in this article, ‘eliminationism’ is defined as “any set of policies, beliefs, and actions that serve to eliminate disability or advocate for its elimination”. See *infra* note 113 for the source of this definition. This is distinct from the definition of eliminationism related to genocide; for that definition, see e.g. Daniel Jonah Goldhagen, *Worse Than War: Genocide, Eliminationism, and the Ongoing Assault on Humanity*. Nevertheless, the terms share commonalities; for example, the five tools of eliminationism in that context are identified by Goldhagen as transformation through suppression, repression, expulsion, prevention of reproduction, and extermination. *Id.*

an integrationist perspective, the idea that disability is inherently *bad* is still prevalent. Anti-eliminationism seeks to preserve dignity, resources, and support for people with disabilities, while also acknowledging and celebrating the diversity that disability itself brings to society.

*A. Eliminationism: A Particular Problem for People with Disabilities*

Eliminationism,<sup>113</sup> for the purposes of this article, is any set of policies, beliefs, and actions that serve to eliminate disability or advocate for its elimination.<sup>114</sup> It is the confluence of factors that combine to reduce the instance of disability in society.

Eliminationism need not be intentionally directed at people with disabilities, yet that is how it is often experienced. At its core, it is different from subordination both in degree and in kind. Anti-eliminationism activism has life and death at stake, but is also frequently pitted against rational justification arguments rather than pernicious stereotyping.<sup>115</sup>

Within disability-rights groups, there is growing concern about issues of eliminationism.<sup>116</sup> These groups have taken the position that anti-eliminationism must be a central component of their advocacy, because it addresses substantial issues that anti-subordination does not: namely, that much of the public sees eliminating disability as a ‘good,’<sup>117</sup> while many disability rights activists disagree.<sup>118</sup> While an anti-subordination perspective might seek to raise up

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113. See Melissa McEwan’s use of the term ‘eliminationism’ in the context of fat-hatred, which is the first use of the term the author has come across outside of writings on genocide. See Melissa McEwan, *On Fat Hatred and Eliminationism*, SHAKESVILLE (Sept. 2, 2011), <http://www.shakesville.com/2011/09/on-fat-hatred-and-eliminationism.html> (discussing the use of the term ‘eliminationism’ in the context of fat-hatred, as opposed to genocide).

114. While this argument is not within the scope of this Article, it is readily acknowledged that other marginalized groups face existential threats as well. The distinction is that people with disabilities feel they are purposefully targeted *with the explicit support of society*; see *infra* section IV. C for the discussion on physician-assisted suicide and more on this idea. However, an anti-eliminationist critique might tie back to critical race theory in the way that anti-subordination theory ties forward to disability. Scholars have noted the attack on black lives in similar fashion; see Jerome McCristal Culp, Jr., *Autobiography and Legal Scholarship and Teaching: Finding the Me In the Legal Academy*, in *CRITICAL RACE THEORY: THE CUTTING EDGE* 490 (Richard Delgado & Jean Stefancic, eds. 2000) for a discussion of the death penalty as applied to black defendants as just one example.

115. See *e.g.* discussion of Assisted Suicide in this article for further discussion on the interplay between rational justifications and stereotyping arguments.

116. See NOT DEAD YET, [notdeadyet.org](http://notdeadyet.org) (opposing assisted suicide and euthanasia as “deadly forms of discrimination.”),

117. See Harlan D. Hahn & Todd L. Belt, *Disability Identity and Attitudes Toward Cure in a Sample of Disabled Activists*, 45 J. HEALTH & SOC. BEHAV. 453, 461-62 (2004).

118. See *Not Dead Yet Disability Activists Oppose Assisted Suicide As A Deadly Form of Discrimination*, NOT DEAD YET, [notdeadyet.org/assisted-suicide-talking-points](http://notdeadyet.org/assisted-suicide-talking-points) for a discussion, which states that “[s]ome people fear disability as a fate worse than death. Proponents of legalized assisted suicide are willing to treat lives ended through assisted suicide coercion and abuse as ‘acceptable losses’ when balanced against their unwillingness to accept disability or responsibility for their own suicide.” *Id.*

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people with disabilities in society, it is ultimately silent on whether disability is, or can be, a neutral proposition in a fully accessible world.

If anti-subordination theory promotes the idea that people with disabilities should be actively included in society through deliberate measures and free from abuse and stigma, then anti-eliminationism argues that disability should not be eradicated entirely from society. This is not just a point about people who currently have a disability, although that is part of the argument, it also extends to *potential* people with disabilities.<sup>119</sup> This potential is both (1) potential people with disabilities, or those who are currently able-bodied, but who may become disabled later; and (2) *potential people*, meaning those people who have not been born yet, and who may never be born. Disability is “a natural part of the human experience.”<sup>120</sup> The range of ways that able-bodied people might suddenly find themselves disabled is vast, from accidental injuries resulting in physical impairments, to substance use disorders, mental illness, and degenerative diseases.

The idea that we *should* strive to eliminate disability, however, is in some respects founded on the notion that a life with a disability may not be worth living, or at least is ‘meaningless’ with a ‘dismal forecast.’<sup>121</sup> One formulation of this view has been expressed by Harriet McBryde Johnson, a disability rights lawyer, who wrote that [those who promote the idea that living with a disability is not a life worth living think]:

it would have been better, all things considered, to have given my parents the option of killing the baby I once was, and to let other parents kill similar babies as they come along, and thereby avoid the suffering that comes with lives like mine... The presence or absence of disability doesn't predict quality of life.<sup>122</sup>

In contrast, anti-eliminationism endorses the affirmation of life with disabilities, not only as freedom from abuse, but also as affirmatively worthwhile in spite of *and because of* disability.

Only certain disabilities, or certain groups of people with disabilities, are typically ‘targeted’ for removal from society. Which groups are targeted is of grave concern, because ‘eliminating’ disability disproportionately harms low-income people, and people already living with disabilities:

Persons or families with disabled children have claimed that a policy that encourages prebirth genetic deselection of persons with disabilities is a public statement that the lives of the disabled are worth less than those of the able-bodied. In addition, such a policy reduces the number of persons with those disabilities, thus reducing their political effectiveness. . . . In short, it engenders

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119. See *e.g. infra* Section IV.E.

120. 42 U.S.C.A § 15001 (A)(1) (WEST. 2000).

121. Harriet McBryde Johnson, *Unspeakable Conversations*, N.Y. TIMES MAGAZINE, (Feb. 16, 2003).

122. *Id.*

or reinforces public perceptions that the disabled should not exist, making intolerance and discrimination toward them more likely.<sup>123</sup>

If it is true that only a portion of disability can be eliminated, then it may be that the people with the least resources will be the most affected. On the other side of this issue are health advocates who say that we must strive to make life better for all, if we can.<sup>124</sup> For some, this could mean the prevention of disability.<sup>125</sup> There has also been scholarship focused on intentionally creating children with disabilities, and whether this is an ethical choice.<sup>126</sup> While these approaches are not the focus of this article, an anti-eliminationist critique may have something to say about parents with disabilities who want to have children with their same disability, if such a position is in fact prevalent.<sup>127</sup>

### *B. Filling the Anti-Subordination Gap with Anti-Eliminationism*

The key component that is missing from much of the disability law literature is an understanding of the anti-eliminationism perspective. The most prolific writing on the issue has been in specific reference to two areas, discussed in the Case Studies *infra*: physician-assisted suicide and reproductive/prenatal testing. However, there are other areas that warrant an anti-eliminationism analysis, and more that may emerge.<sup>128</sup> A more comprehensive understanding and analysis of this position is therefore warranted.

The experience of people with disabilities confronting eliminationism can be seen as pitting the drive to live an autonomous life against a message that such a life might not be worth living. Nonetheless, the policies that enact eliminationist perspectives are usually at least facially neutral, if not intended to *help* people with disabilities. As discussed *infra*, assisted suicide laws do not explicitly state that their goal is to eliminate people with disabilities, even if that is how the effect is felt by people with disabilities.<sup>129</sup>

As Arlene Kanter identifies, disability studies generally, “infuses the legal academy [with] a perspective of those who are routinely made invisible and

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123. John Robertson, *Genetic Selection of Offspring Characteristics*, 76 B. U. L. REV. 421, 423 (1996).

124. See Glenn Cohen, *Intentional Diminishment, the Non-Identity Problem, and Legal Liability*, 60 HASTINGS L.J. 347 (2008) (identifying that some bioethicists argue that intentional disability is always harmful).

125. *Id.* at 349.

126. *Id.*; Kirsten Rabe Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L. J. 299 (2008).

127. See e.g. Darshak M. Sanghavi, *Wanting Babies Like Themselves, Some Parents Choose Genetic Defects*, N.Y. TIMES (Dec. 5, 2006), [http://www.nytimes.com/2006/12/05/health/05essa.html?\\_r=0](http://www.nytimes.com/2006/12/05/health/05essa.html?_r=0) (detailing parental choices in selecting children with disabilities). The anti-eliminationist perspective might be to enhance choice along these lines.

128. See *infra* IV.C. and IV.E.

129. See *infra* Part IV.C. *But see* Peter Singer, PRACTICAL ETHICS 184 (Cambridge Univ. Press, 2d ed. 1995). The exception to this may be Peter Singer, who has (quite controversially) contended that parents may be morally justified in killing some infants at birth who are severely disabled.

marginalized, just as feminist legal studies and critical race theory did before it for other groups.”<sup>130</sup> For Kanter, this means viewing the person with a disability “as one who is limited more by social attitudes and environmental barriers than any inherent ‘defect’ or ‘deficiency’ within the person that must be remedied.”<sup>131</sup> This article suggests that, even more than that contribution, disability law must go further, and take into account the potentially anti-disability forces of subordination and eliminationism.

#### IV. A CONFLICT OF VALUES

Autonomy, anti-subordination, and anti-eliminationism are each crucial pieces of a well-developed theory of disability law. However, they are often in tension. This section will provide concrete examples of those tensions, advocate for increased scrutiny in these areas, and propose some preliminary solutions.<sup>132</sup>

The first section here will provide examples of eliminationism in the context of access to healthcare, in order to illustrate that this problem has yet to be solved.<sup>133</sup>

Next, the second and third examples involve a person with a disability acting autonomously, expressing a wish to exercise autonomy in a manifestly

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130. Kanter, *supra* note 105, at 405-06.

131. *Id.* at 409.

132. THERE IS AN ADDITIONAL TENSION, NOT FULLY EXPLORED IN THIS ARTICLE, WHICH IS BETWEEN A PERSON WITH A DISABILITY AND A PERSON ACTING ON THEIR BEHALF. *SEE E.G.* JENNIFER J. MONTHIE, *THE MYTH OF LIBERTY AND JUSTICE FOR ALL: GUARDIANSHIP IN NEW YORK STATE* 80 *ALB. L. REV.* 947 (2016-17); DUSTIN RYNDERS, *SUPPORTING ADULTS WITH DISABILITIES TO AVOID UNNECESSARY GUARDIANSHIP* 55-FEB *HOUS. L. REV.* 26 (2018); LESLIE SALZMAN, *USING DOMESTIC LAW TO MOVE TOWARD A RECOGNITION OF UNIVERSAL LEGAL CAPACITY FOR PERSONS WITH DISABILITIES*, 39 *CARDOZO L. REV.* 521 (2017).

As discussed *supra* in Section I, the emphasis on ‘rationality’ in autonomy can cut out of decision-making some people with disabilities who act or think ‘irrationally’. If the law then places another individual in charge of decision-making, there is frequently conflict on a number of fronts.

First, the decisions themselves may be contested: the person with a disability wants one thing, while the legal guardian decides to do another. Ideally in this scenario, the guardian is sensitive to a wide array of issues such as the nature of that person’s disability and the importance of trying to honor their wishes. Inevitably, however, there will be times when a guardian makes a decision with which the person with a disability disagrees. What then? What values can the person with a disability appeal to when their autonomy is removed?

The second conflict here is that we can readily imagine scenarios where a guardian might be either ignorant, lazy, biased, or actively malicious. When one person has that level of control over the fate of another, abuse of power is inevitable, even with legal safeguards in place.

Finally, the exercise of guardianship procedures might be seen as an eliminationist move, in that the voices of people with disabilities will necessarily be diminished. Is there another way to account for, care for, and protect people with profound disabilities who truly cannot make necessary decisions?

These conflicts are unfortunately left unresolved here, as they are outside the scope of this particular Article.

133. *See infra* Section IV.A. (detailing the problem of access to health care).

concrete way – by choosing to die, or choosing to engage in sexual activity.<sup>134</sup> These examples also have in common that a disability-rights-focused perspective may run counter to the manifestation of that autonomy. In the case of sexual activity, anti-subordination's concern with the potential for abuse, exploitation, and the difficulty in determining true consent is examined.<sup>135</sup> In the case of physician-assisted suicide, it is a death that is being faced, and anti-eliminationism weighs towards at least discouraging that death, if not more<sup>136</sup>

Finally, the fourth and fifth examples take a look at actors who make decisions on behalf of people with disabilities. These actors, as decision-makers, make decisions that can subject people with disabilities to subordination, or involve a choice about whether or not to produce a child with a disability. These decision-makers may or may not have disabilities themselves, which may affect their decision-making. However, the salient disabled person in these cases is the object of the decision: the disabled child, or the potential child.<sup>137</sup>

#### *A. Problems with Access to Healthcare*

The resistance that some people with disabilities experience when attempting to access healthcare fits squarely within an anti-eliminationist critique. People with disabilities should be afforded the same access to healthcare as others, but are frequently denied it.<sup>138</sup>

One example is organ transplantation for people with intellectual and developmental disabilities.<sup>139</sup> A policy brief published in March 2013 by the Autistic Self Advocacy Network (ASAN) identified discriminatory practices which deny people with disabilities from receiving necessary organ transplants.<sup>140</sup> An example given in the brief identifies a woman with Down syndrome who was denied a heart and lung transplant by two hospitals.<sup>141</sup> One

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134. See *infra* Section IV.B. and IV.C. (detailing examples of autonomous choice by people with disabilities).

135. Two other related issues along these dimensions include the controversy within the deaf community over cochlear implants for the profoundly deaf, see e.g. Lydia Denworth, *Science Gave my Son the Gift of Sound*, TIME April 25, 2014, especially "A Cure or A Genocide?", <https://time.com/76154/deaf-culture-cochlear-implants/>, and California law AB 1014, which authorizes courts to issue Gun Violence Restraining Orders to remove an otherwise legally-owned gun from an individual who exhibits certain behaviors associated with mental illness, 2014 Cal. Legis. Serv. Ch. 872 (A.B. 1014) (WEST).

136. See *infra* Section IV.C. (detailing choice as imposed on a person with disabilities).

137. See *infra* Section IV.D. and IV.E.

138. See e.g. Ari Ne'eman et al., *Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps* (March 2013), AUTISTIC SELF ADVOCACY NETWORK [http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief\\_3.18.13.pdf](http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf). (describing organ transplant policies that discriminate against people with certain disabilities)

139. *Id.*

140. *Id.*

141. *Id.*

hospital stated that such transplants were categorically inappropriate for people with Down syndrome, and the other hospital did not find any medical reason to refuse the transplant, but denied her because it concluded that “her condition made her unable to follow the complex post-transplantation medical regiment that would be required of her.”<sup>142</sup>

The problem combines the most pernicious aspects of stigma, stereotyping, and bias: the idea that people with disabilities either aren’t ‘worthy’ of life-saving transplants or wouldn’t be able to ‘handle’ them anyway.<sup>143</sup> This concern is born out by a recent letter sent to the U.S. Department of Health and Human Services’ Office for Civil Rights (“OCR”), signed by 30 members of the U.S. House of Representatives, which “urged the agency to address what they called ‘persistent’ organ transplant discrimination.”<sup>144</sup>

Indeed, as recently as September 2018, a complaint was lodged with the OCR indicating that the University of North Carolina Health Care system denied “a person with intellectual disability the opportunity to be placed on a transplant list.”<sup>145</sup> The complaint alleged that:

an individual with an intellectual disability was in need of a heart transplant, but a doctor on staff at UNC Health Care determined that they were not a good candidate for heart transplant because of their developmental learning disabilities and because they do not live independently. The complainant asserted that without the transplant, they would eventually die.<sup>146</sup>

### *B. Consent to Sexual Activity*

Gaining sexual autonomy has long been a struggle for people with disabilities.<sup>147</sup> People with intellectual disabilities in particular face assumptions

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142. *Id.*

143. *Id.* See also Michelle Diament, *Disability No Reason to Deny Organ Transplants, Lawmakers Say*, DISABILITYSCOOP, (Oct. 24, 2016) (describing an effort by members of the U.S. House of Representatives to urge the U.S. Department of Health and Human Services to cease the practice of discrimination against people with disabilities in organ transplant).

144. Diament, *supra* note 143.

145. Shaun Heasley, *Feds: Patient with Intellectual Disability Blocked From Organ Transplant List*, DISABILITY SCOOP (February 18, 2019), <http://www.disabilitycoop.com/2019/02/18/feds-blocked-transplant-list/26055>.

146. Press Release, HHS Press Office, *OCR Resolves Disability Complaint of Individual Who Was Denied the Opportunity for Heart Transplant List Placement* (February 12, 2019), <http://www.hhs.gov/about/news/2019/02/12/ocr-resolves-disability-complaint-individual-who-was-denied-opportunity-heart-transplant-list.html>.

147. See generally MICHAEL GILL, *ALREADY DOING IT: INTELLECTUAL DISABILITY AND SEXUAL AGENCY* (2015).

A related issue, though not the focus of this paper, is the struggle to gain the autonomy, freedom, and right to bear and raise children. The Supreme Court’s decision in *Buck v. Bell*, 274 U.S. 200 (1927) upheld the compulsory sterilization of the ‘unfit,’ including people with (or alleged to have) intellectual disabilities. See also Beth Ribet, *Surfacing Disability Through A Critical Race Theoretical Paradigm*, 2 GEO. J.L. & MOD. CRITICAL RACE PERSP. 209 (2010) for issues relating to the use of the disability label as a weapon

that they are ‘child-like’ and not desirous of sexual lives, or that they should be ‘protected from themselves’ if they are.<sup>148</sup> One variation of this stereotype is that people with intellectual disabilities are “uncontrollably and inappropriately sexual.”<sup>149</sup>

Adults living with Down syndrome frequently experience these assumptions and stereotypes.<sup>150</sup> According to the National Down Syndrome Society, “[i]n the past, sexuality was not considered an issue for any people with Down syndrome because of the inaccurate belief that intellectual disability (formerly known as mental retardation) produced permanent childhood. In fact, all people with Down syndrome have sexual feelings and intimacy needs.”<sup>151</sup>

Moreover, people with Down syndrome struggle to gain acceptance when they engage in romantic and sexual relationships.<sup>152</sup> In contrast, when competency to consent along with an acknowledgement of sexual desire are presumed absent, sexual encounters with people with disabilities are “automatically assumed to be assault – they have to be proven otherwise in criminal and legal mechanisms”.<sup>153</sup>

Adding further complexity, ableism in this context is linked to heteronormativity.<sup>154</sup> Robert McRuer tracks the visibility of disability (or of ‘crips’ in his terminology) with the visibility of queerness, arguing that the

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of sexual oppression. *Buck v. Bell* has never been overturned; *Skinner v. Oklahoma*, 316 U.S. 535 (1942) limited the scope of some compulsory sterilization laws, but did not directly comment on sterilization of the disabled. In fact, involuntary sterilization still occurs. As recently as 2014, a 20-year-old man with an intellectual disability had to sue to prevent his mother from having a doctor perform an involuntary vasectomy on him. *See Kennedy v. Kennedy*, 845 N.W.2d 707 (Iowa, 2014) (holding that Court-approved involuntary vasectomies would be acceptable under certain circumstances; it was that the man’s mother had neglected to seek a judicial order first that was the problem).

Furthermore, once a child is born to someone with a disability, there is frequent state intervention to discourage or prevent that parenting relationship. *See* NAT’L COUNCIL ON DISABILITY, *ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN*, (September 27, 2012), [http://www.ncd.gov/rawmedia\\_repository/89591c1f\\_384e\\_4003\\_a7ee\\_0a14ed3e11aa.pdf](http://www.ncd.gov/rawmedia_repository/89591c1f_384e_4003_a7ee_0a14ed3e11aa.pdf) (explaining the differences that parents with disabilities are more likely to face, such as removal of their children, termination of their parental rights, discrimination in custody, difficulty in accessing assistive reproductive technology, and face barriers to adoption). *See also* Joint Letter from the U.S. Dep’t of Just. & Health and Hum. Services To Interim Comm’r Erin Deveney, (Jan. 29, 2015) (describing the bias in the Massachusetts child welfare system against parents with disabilities, and asserting that the Americans with Disabilities Act applies in the child welfare law context), [https://www.ada.gov/ma\\_docf\\_lof.pdf](https://www.ada.gov/ma_docf_lof.pdf).

148. *Id.*

149. *Id.* at 30.

150. *See Sexuality & Down Syndrome*, NAT’L DOWN SYNDROME SOC’Y, <https://www.ndss.org/resources/sexuality/>.

151. *Id.*

152. *See, e.g.* Clair Pullen, *Couples with Down Syndrome Don’t Need To Be Sterilized, They Need Support*, SYDNEY MORNING HERALD, (October 6, 2016) <https://www.smh.com.au/lifestyle/couples-with-down-syndrome-dont-need-to-be-sterilised-they-need-support-20161005-grv6no.html> (describing two adults with Down syndrome whose parents sought to have them forcibly sterilized).

153. Gill, *supra* note 147.

154. MCGRUER, *supra* note 8.

system of compulsory of able-bodiedness that produces disability is interwoven with and dependent on the system of compulsory heterosexuality that produces queerness.<sup>155</sup> This system is dependent on able bodies being ‘invisible’ in the same way that heterosexuality is: it is the default, the assumption, and not worthy of note.<sup>156</sup> When disabled bodies are by contrast visible, they are visible for their difference, and therefore are seen as having something different about their sexuality too.<sup>157</sup>

Paternalistic over-protection on the one hand, at the expense of inhibiting sexual autonomy, is contrasted with the high risks of exploitation, a concern of anti-subordination.<sup>158</sup> People with disabilities, and women with disabilities in particular, are subject to high rates of sexual abuse; some estimates put the rate at 80% of women with intellectual disabilities abused in their lifetime.<sup>159</sup> Not only are people with disabilities more than twice as likely to be victims of violent crime as people without disabilities, people with disabilities are more than *three times* as likely to be the victims of *serious* violent crime (rape or sexual assault, robbery, and aggravated assault) as people without disabilities.<sup>160</sup>

Undoubtedly, protection from sexual assault must be a priority, and any group sexually assaulted at such an alarming rate urgently needs that protection. How to address this problem, “without making the victims symbols of humiliation,” while also acknowledging the “social forces such as ableism, racism, classism, and sexism that portray women with intellectual disabilities as warranting special treatment,”<sup>161</sup> is the challenge here.

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155. *Id.*

156. *Id.*

157. *Id.*

158. *See id.* *See also Sexual Assault Within Underserved Populations*, THE WASH. COAL. OF SEXUAL ASSAULT PROGRAMS, <https://www.wcsap.org/help/about-sexual-assault/how-often-does-it-happen> (last visited April 1, 2019) (providing data on the high risk of sexual assault among people with disabilities, particularly people with development disabilities).

159. According to some sources, 80% of women and 30% of men with intellectual disabilities have been sexually assaulted, and 50% of those women were assaulted more than ten times. *Sexual Assault Within Underserved Populations*, THE WASH. COAL. OF SEXUAL ASSAULT PROGRAMS, <https://www.wcsap.org/help/about-sexual-assault/how-often-does-it-happen> (last visited April 1, 2019); DISABILITY JUSTICE, SEXUAL ABUSE <https://disabilityjustice.org/sexual-abuse>; DISABLED WORLD, PEOPLE WITH DISABILITIES AND SEXUAL ASSAULT, <https://www.disabled-world.com/disability/sexuality/assaults.php#ixzz2SXMEQWra>. The rates of abuse may also be higher for physical disabilities; for example, 54% of boys who are Deaf have been sexually abused, compared to 10% of boys who are hearing, and 50% of girls who are Deaf have been sexually abused, compared to 25% of girls who are hearing. *See also* Patricia Sullivan et al., *Sexual Abuse of Deaf Youth*, 132 AM ANN DEAF 256 (1987).

160. *Crime Against Persons with Disabilities, 2009-2014 Statistical Tables*, BUREAU OF JUST. STAT. (2016), [https://www.bjs.gov/content/pub/pdf/capd0914st\\_sum.pdf](https://www.bjs.gov/content/pub/pdf/capd0914st_sum.pdf).

161. Gill, *supra* note 147, at 23.

One proposal is to adjust the concern with consent by centering a concern about *exploitation*.<sup>162</sup> H. Matthews defines abuse as based on the presence of exploitation – this is helpful “because it moves away from the albeit crucial issue of consent and indicates that although a person with learning disabilities may have been willing to engage in sexual contact, they may still have been abused, because of the position or motivation of the other person.”<sup>163</sup> This focus on exploitation rather than consent recognizes that there may be an “unequal power dynamic” that favors “professionals, family members and staff,” which can lead to sexual violence.<sup>164</sup>

An exploitation analysis would be an anti-subordination-based response to the problem in that it could allow people with intellectual disabilities, for example, to engage in romantic and/or sexual relationships without turning them into “symbols of humiliation” or seeing them as “warranting special treatment.”<sup>165</sup>

Take the case of *State v. Fourtin*, in which Richard Fourtin was accused of sexually assaulting a woman with cerebral palsy and hydrocephalus who used a wheelchair.<sup>166</sup> The decision focused on the consent issue – it appeared to the Connecticut Appellate Court that the alleged victim was capable of consent because she had a history of “registering displeasure” through “biting, kicking and scratching.”<sup>167</sup>

If the focus of that decision had been on exploitation - rather than capacity to consent - it may have come out differently. Prosecutors argued in the case that the alleged victim (referred to as “L.K.”) was “physically helpless.”<sup>168</sup> The finding of physical helplessness was necessary for Fourtin’s conviction under the Connecticut statute for sexual assault in the second and fourth degrees.<sup>169</sup> Physical helplessness is defined as “unconscious or for any other reason... physically unable to communicate unwillingness to an act.”<sup>170</sup>

The Connecticut Court was probably correct that under the statute, L.K. did not meet the definition of physically helpless<sup>171</sup> If she was capable of communicating her unwillingness to an act, essentially, she was capable of

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162. Michelle McCarthy & David Thompson, *Sexual Abuse by Design: An Examination of the Issues in Learning Disability Services*, 11 DISABILITY AND SOC’Y 205, 206 (1996).

163. *Id.*

164. Gill, *supra* note 147, at 34.

165. *Id.*

166. *State v. Fourtin*, 52 A.3d. 674 (Conn. 2012)

167. *Id.* at 677; see also Joseph Fischel & Hilary O’Connell, *Disabling Consent, Or Reconstructing Sexual Autonomy*, 30 COLUM. J. GENDER & L. 428, 429 (2016) (describing the *Fourtin* case and decision).

168. *Id.*; Fischel & O’Connell, *supra* note 167, at 474.

169. *Id.*

170. *Id.*

171. *State v. Fourtin*, 52 A.3d. 674 (Conn. 2012).

consent (or, as the case may be, non-consent).<sup>172</sup> Perhaps, then, the issue was the charging statute; why not prosecute Fourtin under a rape statute without the ‘physical helplessness’ dimension? There were two other options in the case available to prosecutors: The general sexual assault statute, which requires proof of physical force, and a sexual assault statute that relates to victims determined to be “mentally defective.”<sup>173</sup> Since L.K.’s disability rendered it unnecessary to use physical force to assault her, the only other option available to prosecutors would have been to prove she was ‘mentally defective.’<sup>174</sup>

After the case and directly in response to it, 2012 statutory revisions added a provision regarding when a victim’s ability to consent is impaired “because of mental disability.”<sup>175</sup> This also seems unsatisfactory.. If a person were covered by this statute it is true that their lack of consent, if present, would be accounted for; however, it also removes any possibility for their sexual autonomy, or “*wanted* sexual contact.”<sup>176</sup> Perhaps it would not be necessary to remove a victim’s agency, her ability to consent, if the law allowed the Court to focus on *exploitation* instead. An affirmative-consent standard might also be helpful by allowing the court to inquire as to whether the victim expressed any willingness to engage in the sexual encounter; rather than only considering evidence of her unwillingness.<sup>177</sup>

### C. Physician-Assisted Suicide

Ben Mattlin, in an op-ed for the *New York Times* about a proposed assisted-suicide law in Massachusetts, explained the problem:

I’ve lived so close to death for so long that I know how thin and porous the border between coercion and free choice is, how easy it is for someone to inadvertently influence you to feel devalued and hopeless – to pressure you ever so slightly but decidedly into being ‘reasonable,’ to unburdening others, to ‘letting go.’<sup>178</sup>

Mattlin, born with spinal muscular atrophy, takes the position of many disability rights advocates that “right to die” legislation is fraught with the potential for abuse, too wrapped up in the everyday coercion and social pressure

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172. *Id.*

173. CONN. GEN. STAT. ANN. § 53a-65(4) (West 2015); *See also* Fischel & O’Connell, *supra* note 169, at 479 (describing the law at issue in *Fourtin*).

174. Fischel & O’Connell, *supra* note 167.

175. *Id.* at 480-81.

176. *Id.* at 482.

177. *Id.* at 493. It is worth noting that a focus on exploitation would not necessarily be radical, as much of criminal law maintains a *mens rea* element that looks to what was inside the defendant’s mind at the time an act was committed.

178. Ben Mattlin, *Suicide by Choice? Not So Fast*, N.Y. TIMES: THE OPINION PAGES (Oct. 31 2012) <https://nyti.ms/Y2AI3p>.

for disabled people to end their lives.<sup>179</sup> After all, “Who chooses suicide in a vacuum?”<sup>180</sup>

What greater expression of truly ‘owning one’s life’ could there be than deciding the place and manner of one’s own death? In that sense, suicide is the ultimate expression of autonomy. Sylvia Law writes, “the right to choice is valuable, however that choice is exercised. The dying patient has lost control of most significant aspects of his or her life. The assurances that assisted death is an option provides a measure of autonomy and control, however that autonomy is exercised.”<sup>181</sup>

This notion is contrasted with concerns about coercion based on societal stigma and bias.<sup>182,183</sup> The debate sets up a real problem for assisted suicide laws. Robert Burt writes that we should be skeptical of these laws because “we fool ourselves if we think that patient control - that the self-determination ideal - is an adequate corrective to these abuses. We fool ourselves if we imagine that this ideal does not carry its own dark implications.”<sup>184</sup>

Physician-assisted suicide is currently legal in California,<sup>185</sup> Colorado,<sup>186</sup> Hawaii,<sup>187</sup> Maine,<sup>188</sup> Oregon,<sup>189</sup> Vermont,<sup>190</sup> Washington,<sup>191</sup> Montana,<sup>192</sup> and Washington D.C.<sup>193</sup> A law is pending in New Jersey<sup>194</sup> These statutes<sup>195</sup> typically rely on doctors’ determinations that a person has a terminal illness, and a voluntarily expressed wish to receive medication that will end the person’s life.

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179. See generally *Id* (arguing against assisted-suicide laws from a disability-rights perspective).

180. *Id.*

181. Sylvia Law, *Physician-Assisted Death: An Essay On Constitutional Rights and Remedies*, 55 MD. L. REV. 292, 298-99 (1996).

182. Samuel Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J.L. & GENDER 425, 426 (2006) (“societal stigmas and other social pressures effectively coerce people into making decisions that reflect biases against people with disabilities”).

183. Robert Burt, *Rationality and Injustice in Physician-Assisted Suicide*, 19 W. NEW ENG. L. REV. 353 (1997).

184. Burt, *supra* note 14.

185. END OF LIFE OPTION ACT, CAL. HEALTH & SAFETY CODE § 443-444.12.

186. Colorado End of Life Options Act, Proposition 106.

187. Our Care, Our Choice Act, HRS § 327L-1.

188. Maine Death with Dignity Act.

189. Oregon Death with Dignity Act, OR. ST. § 127.800.

190. Patient Choice at End of Life Act, VT. STAT. ANN. TIT. 18 §§ 5291-5293 (2019).

191. the Washington Death with Dignity Act, WASH. REV. CODE §§ 70.245.010-70.245.903 (2019).

192. *Baxter v. Montana*, 354 Mont. 234 (Mont. 2009).

193. District of Columbia Death with Dignity Act of 2016 D.C. Law 21-182.

194. Assemb. B. 1504, 2018 Gen. Assemb., Reg. Sess. (N.J. 2018); the law is pending a court challenge. See <https://www.deathwithdignity.org/states/new-jersey/>.

195. The majority of the states have passed statutes. The exception is Montana, referenced in note 194, where PAS is legal by order of the court.

This is of particular concern for people with disabilities, who make up a large subset of people requesting access to lethal prescriptions.<sup>196</sup>

For example, the Oregon statute provides:

(1) An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 to 127.897.

(2) No person shall qualify under the provisions of ORS 127.800 to 127.897 solely because of age or disability.<sup>197</sup>

While this statute contains a requirement for a referral for counseling if the physician determines the patient may have a psychiatric disorder or depression causing impaired judgment, there is no requirement for any standard depression screening or mental health evaluation.<sup>198</sup>

Disability rights groups have argued that people with disabilities, particularly those who are identified as ‘terminal,’ are more likely to experience feelings of depression, of being a burden, and other mental states that might be alleviated with services or other interventions.<sup>199</sup>

The opposition to assisted suicide legalization has been framed as an effort to “oppose of assisted suicide and euthanasia as deadly forms of discrimination.”<sup>200</sup>

There is data to support the proposition that these laws may harm people with disabilities. One issue is the problematic identification of ‘terminal’ patients,<sup>201</sup> and Oregon’s data confirms that ‘non-terminal’ people with

196. *Oregon Public Health Division Report: “Oregon’s Death With Dignity Act – 2014,”* OR. PUB. HEALTH DIV., <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> (last visited Apr. 8, 2019).

197. OREGON DEATH WITH DIGNITY ACT, OR. REVISED STAT. §127.805 S 2.01.

198. *Id.* at 127.825 § 3.03.

199. *Not Yet Dead Disability Activists Oppose Assisted Suicide As A Deadly Form Of Discrimination*, NOT YET DEAD, <http://notdeadyet.org/assisted-suicide-talking-points> (last visited Apr. 8, 2019).

200. *Id.*

201. They rely on a prediction of what will be a ‘terminal’ illness by a doctor, which could be flawed. E.B. Lamont et al., *Some Elements Of Prognosis In Terminal Cancer*, ONCOLOGY (HUNTINGTON), 1165-1170 (1999); M. Maltoni, et al., *Clinical Prediction Of Survival Is More Accurate Than The Karnofsky Performance Status In Estimating Lifespan Of Terminally-Ill Cancer Patients*, EUR. J. OF CANCER, 764-66 (1994); N.A. Christakis and T.J. Iwashyna, *Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists*, ARCHIVES. OF INTERNAL MED., 2389-95 (1998).; J. Lynn et al., *Prognoses Of Seriously Ill Hospitalized Patients On The Days Before Death: Implications For Patient Care And Public Policy*, NEW HORIZONS, 56-61 (1997).

“17 percent of patients [outlived their prognosis] in the Christakis study. This roughly coincides with data collected by the National Hospice and Palliative Care Organization, which in 2007 showed that 13 percent of hospice patients around the country outlived their six-month prognoses. ... When a group of researchers looked specifically at patients with three chronic conditions—pulmonary disease, heart failure, and severe liver disease—they found that many more people outlived their prognosis than in the Christakis study.

disabilities have received lethal prescriptions.<sup>202</sup> Ninety one percent of people requesting lethal medications in Oregon reportedly made their request due to “*loss of autonomy*” (emphasis added).<sup>203</sup> To return to this Article’s main concern, ‘owning one’s life’ in this context is in direct potential conflict with anti-eliminationism.

Solutions to these concerns could be as simple as additional regulatory measures.<sup>204</sup> According to disability rights advocates, however, this is not sufficient.<sup>205</sup> For them, only a complete ban on physician-assisted suicide is sufficient.<sup>206</sup> The dangers of exploitation, coercion, misdiagnosis, and suicide based on depression or feelings of being a burden, are too high.<sup>207</sup>

On the other hand, as with many outlawed practices, a ‘ban’ in law means unregulated action in practice. If the practice were again illegal, it might “continue illicitly and without institutional safeguards.”<sup>208</sup> Sylvia Law argues that such a ban would parallel pre-legalization abortion, where “abortions were performed, but because they were illegal, they were costly, clandestine, and often of poor quality.”<sup>209</sup> Nevertheless, disability activists say, the risks and problems of legalized physician-assisted suicide outweigh the risks and problems of an illegal status.<sup>210</sup> Moreover, the message that is sent by legal physician-assisted

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Fully 70 percent of the 900 patients eligible for hospice care lived longer than six months, according to a 1999 paper published in the Journal of the American Medical Association.” Nina Shapiro, *Terminal Uncertainty*, SEATTLE WEEKLY (2009), <http://archive.seattleweekly.com/2009-01-14/news/terminal-uncertainty/>.

202. The state report reveals that people outlived the six-month ‘terminal’ prognosis regularly, based on the time lapse between the person’s request for assisted suicide and their death. The reported time lapses ranged up to 1009 days. Oregon Public Health Report *supra* note 198.

203. *Supra* note 196.

204. *See supra* note 197. Oregon already allows physicians to ask for a psychological consult, for example, where necessary; one could imagine a requirement for a depression screening for every person seeking physician-assisted suicide.

205. *Assisted Suicide Laws*, DISABILITY RIGHTS EDU. & DEFENSE FUND, [dredf.org/public-policy/assisted-suicide](http://dredf.org/public-policy/assisted-suicide).

206. The Disability Rights Education & Defense Fund (DREDF) “opposes the legalization of assisted suicide and euthanasia.” The group argues that “[l]egalization is a serious mistake for many reasons that are not always immediately apparent. Supporters often focus solely on issues of choice and self-determination, but actually, legalization would restrict choice and self-determination. . . It is imperative to distinguish personal wishes from the significant dangers to society of legalizing assisted suicide as public policy.” *Id.*

207. *So-Called Safeguards and Minimal Oversight: The Assisted Suicide Law In Oregon*, DISABILITY RIGHTS EDU. & DEFENSE FUND, [dredf.org/public-policy/assisted-suicide/Oregon-so-called-safeguards-and-minimal-data](http://dredf.org/public-policy/assisted-suicide/Oregon-so-called-safeguards-and-minimal-data).

208. Law, *supra* note 181, at 310.

209. *Id.* at n. 87.

210. *Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide*, NOT DEAD YET <http://notdeadyet.org/disability-rights-toolkit-for-advocacy-against-legalization-of-assisted-suicide>.

suicide is in some ways just as important for activists: these laws indicate to them that the state itself is saying that disabled lives are not worth living.<sup>211</sup>

*D. Neurodiversity, Anti-Autism, and the Deaf response to cochlear implants*

The next example of the tension between autonomy and anti-subordination comes from Autistic activists arguing against what they see as “anti-Autism” rhetoric.<sup>212</sup> One visible example comes from the anti-vaccination movement, which has had as one of its driving forces the now-discredited study linking vaccines to Autism.<sup>213</sup> The contention has been that parents should choose to avoid vaccines in order to protect the health of their children – and avoid Autism.<sup>214</sup> While the science has seemingly moved on, some parents have not; a Pew study found that almost one in ten Americans do not believe vaccines are safe,<sup>215</sup> and a small internet survey in 2015 found that one in five people aged 18-29 believe that vaccines cause autism.<sup>216</sup>

However, the anti-vaccination movement is not the only place that anti-Autism rhetoric is prominent. Some parents’ organizations have compared having a child with Autism to having a child stolen from them, or losing a child to a deadly disease.<sup>217</sup> Part of the problem here, and perhaps a solution, is representation.<sup>218</sup> Many Autistics argue that they should be included at every level of advocacy and research about autism.

While it is not clear exactly how many parents may not be vaccinating their children due to specific concerns about Autism,<sup>219</sup> they do generally have a legal

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211. See *Id.* (writing that “some people get suicide prevention while others get suicide assistance, and the difference between the two groups is the health status of the individual, leading to a two-tiered system that results in death to the socially devalued group. This is blatant discrimination.”).

212. See, e.g., Sarah Kurchak, *I’m Autistic, and Believe Me, It’s a Lot Better Than Measles*, THE ARCHIPELAGO (2015), <https://medium.com/the-archipelago/im-autistic-and-believe-me-its-a-lot-better-than-measles-78cb039f4bea>.

213. Clyde Haberman, *A Discredited Vaccine Study’s Continuing Impact on Public Health*, N.Y. TIMES (Feb. 1, 2015).

214. See *id.* (reporting on parents who do not vaccinate their children due to the discredited link between vaccines and autism).

215. Sam Frizell, *Nearly One In Ten Americans Think Vaccines Are Unsafe*, TIME (Feb. 9, 2015).

216. Peter Moore, *Young Americans Most Worried About Vaccines*, YOUNGOV: LIFESTYLE (Jan. 30 2015, 12:01 p.m.), <https://today.yougov.com/topics/lifestyle/articles-reports/2015/01/30/young-americans-worried-vaccines>.

217. E.g., Emily Willingham, *Why Autism Speaks Doesn’t Speak For Me*, FORBES (Nov. 13, 2013, 9:24 p.m.), <https://www.forbes.com/sites/emilywillingham/2013/11/13/why-autism-speaks-doesnt-speak-for-me/#3868a32a3152>.

218. See e.g., *2014 Joint Letter To The Sponsors Of Autism Speaks*, AUTISTIC SELF ADVOCACY NETWORK (Jan. 6, 2014), <http://autisticadvocacy.org/2014/01/2013-joint-letter-to-the-sponsors-of-autism-speaks/> (criticizing the group Autism Speaks for, *inter alia*, failing to include autistic people on its board or in leadership positions).

219. See Gabriella Vukelic, *Pediatricians and the Pushback Against Vaccinations*, ARIZ. NEWS SERV. (Sept. 19, 2016) (noting that refusal of vaccines increased from 2006 to 2013 but refusal due to fear of autism declined over the same time period).

right to make that choice. States generally require that children be vaccinated to attend public school, but offer exceptions for medical, religious or philosophical reasons, as well as the possibility of private or home schooling.<sup>220</sup> If parents make this choice due to concerns about Autism, their rhetoric about avoiding Autism can be damaging.

How this rhetoric has impacted people living with Autism (or autistic people, as that term is preferred by many<sup>221</sup>), and how the rhetoric affects the choices that parents make as somehow “owners” of the children’s lives, is of concern to people with disabilities. Some Autistics argue that talk about finding a ‘cure’ for Autism is misguided – the focus should be on conceptualizing autism as part of “normal human diversity.”<sup>222</sup>

This represents the significant advocacy around ‘neurodiversity’ – a movement to promote acceptance of the “range of thought patterns and behaviors that characterize autism.”<sup>223</sup> One study found that there are significant benefits for some Autistics in certain preferred interests<sup>224</sup>, while some see autism as an “opportunity” not a “weakness.”<sup>225</sup>

A second example of autonomous actors making decisions on behalf of their children comes from an advancement that many see as a positive development: cochlear implants. A cochlear implant is a “small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing.”<sup>226</sup> Deaf and hard-of-hearing children as young as 12 months old are approved to use cochlear implants.<sup>227</sup>

Parents of profoundly deaf or hard-of-hearing children are tasked with making the decision for their children of whether to pursue a cochlear implant or not. The implants are most effective for children when they are implanted at a

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220. See *States with Religious and Philosophical Exemptions from Immunization School Requirements*, NAT’L CONF. OF STATE LEG., (Jan. 30, 2019), <http://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>. (outlining state immunization exemptions to highlight legal rights for parents to withhold vaccinations from their children in religious or philosophical contexts).

221. For example, in an article for the New York Times, Amy Harmon details the perspective of one Ms. Dawson, who in her own words describes herself as an autistic person: “I would appreciate it, if I end up in your article, if you describe me as ‘an autistic’ or ‘an autistic person,’ versus the ‘person with,” “Just like you would feel odd if people said you were a ‘person with femaleness.” Harmon, *supra* note 12.

222. Elizabeth Picciuto, *They Don’t Want An Autism Cure*, THE DAILY BEAST (Feb. 25, 2015).

223. *Id.*; see also Harmon, *supra* note 12 (discussing Autistic identity).

224. Shaun Heasley, *Study: For Those with Autism, Fixations can be Beneficial*, DISABILITY SCOOP (Feb. 3, 2017), <http://www.disabilityscoop.com/2017/02/03/study-autism-fixations/23270/>.

225. Saba Salman, *Interview: ‘I saw being autistic as an opportunity, not a weakness’*, THE GUARDIAN (Jan. 31, 2017), <https://www.theguardian.com/society/2017/jan/31/autism-employment-campaigner-jonathan-andrews>.

226. U.S. DEP’T HEALTH & HUM. SERV., NAT’L INST. ON DEAFNESS AND OTHER COMM. DISORDERS (NIDCD), *Cochlear Implants Fact Sheet* (Mar. 2011), <https://www.nidcd.nih.gov/sites/default/files/Documents/health/hearing/FactSheetCochlearImplant.pdf>.

227. *Id.*

young age, so early decisions can be critical.<sup>228</sup> This means that the choice of whether or not to accept the implant is often made before the child has an opportunity to choose – the decision is made by the parent, who essentially determines if the child will be Deaf or not.

This is a problem for many Deaf people, who argue that making this choice on behalf of a child is inappropriate. Cochlear implants have been called an “affront to [Deaf] culture.”<sup>229</sup> The argument from the Deaf community is that there is nothing about deaf individuals that needs to be “fixed.”<sup>230</sup> Deaf protesters at the “Listening and Spoken Language Symposium” in 2013, which featured some affiliations with cochlear implant manufacturers, argued that the use of the implants largely stems from “miseducating the parents of Deaf children.”<sup>231</sup>

This concept of miseducation – that parents (and potential parents) are being influenced by stereotypes and outdated ideas about life with a disability, is echoed below in the next section, which discusses parents who make choices about whether to birth a child with a disability.

#### *E. Prenatal Genetic Testing*

During pregnancy, birth parents face a variety of choices. One of those choices is whether to engage in prenatal testing for disabilities.<sup>232</sup> Currently available tests include “amniocentesis, chorionic villus sampling, fetal nasal bone measurements, nuchal translucency screening, blood tests (e.g. triple/quad screens, maternal serum screening, alpha-fetoprotein tests), ultrasounds, urine tests, and others.”<sup>233</sup> If a potential issue is discovered, the parents face a second choice: what to do with that information. Choices such as abortion on the basis of the likelihood of the fetus developing a disability are, to say the least, controversial.<sup>234</sup> Prenatal testing is available that can identify a wide variety of potential conditions.<sup>235</sup> This section will discuss whether those choices might harm people with disabilities from an anti-eliminationism perspective, and

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228. Paul Oginni, *UCI Research with Cochlear Implants No Longer Falling On Deaf Ears*, NEW UNIVERSITY, (2009) (“Young children tend to have better post-implantation results since they are still in the language development phase of their lives.”).

229. *The Cochlear Implant Controversy*, CBSNEWS.COM, (June 2, 1998, 2:27 PM) <https://www.cbsnews.com/news/the-cochlear-implant-controversy/>.

230. *Id.*

231. Allegra Ringo, *Understanding Deafness: Not Everyone Wants to Be ‘Fixed’*, THE ATLANTIC (2013).

232. See Carol Bishop Mills and Elina Erzikova, *Prenatal Testing, Disability, and Termination: An Examination of Newspaper Framing*, 32 DISABILITY STUDIES Q. 3 (2012) (discussing the various options available for prenatal disability testing and the publicity of those options).

233. *Id.* at 9.

234. See Bagenstos, *supra* note 182 (discussing the intermingling of pro-life and pro-choice positions on abortion with disability-related cases).

235. *Id.* at 438-39.

whether it is necessary to infringe on autonomy in order to account for that perspective.<sup>236</sup>

One critique of prenatal testing states that it is “morally problematic, and that it is driven by misinformation.”<sup>237</sup> Another argues that “[t]he practices of genetic and prenatal testing as well as physician-administered euthanasia then become potentially eugenic practices within the context of a culture deeply intolerant of disability.”<sup>238</sup> These critiques are very similar to those of physician-assisted suicide, discussed *infra* in Section IV.C.. The key differences here are the identities of the autonomous actor and the object of that action. A birth parent making a decision regarding whether to terminate a pregnancy on the basis of genetic testing is different from a person deciding whether to end their *own* life, but such decision-makers might be subject to similar influences.<sup>239</sup> For example, genetic counselors may “have a tendency (subtly or not) to urge pregnant women to subject their fetuses to prenatal testing and abort fetuses with disabilities.”<sup>240</sup>

From an anti-eliminationist perspective, terminating a pregnancy for these reasons may signal that people with disabilities are less valued, or resources for people with disabilities may be reduced if fewer people have a particular disability. Consider the argument referenced in the discussion of subordination, *infra*, that “a policy that encourages prebirth genetic deselection of persons with disabilities is a public statement that the lives of the disabled are worth less than those of the able-bodied. In addition, such a policy reduces the number of persons with those disabilities, thus reducing their political effectiveness. . . . In short, it engenders or reinforces public perceptions that the disabled should not exist, making intolerance and discrimination toward them more likely.”<sup>241</sup>

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236. There has been a great deal of ink spilled on the subject of genetic prenatal testing and selective abortion; this Article only touches on the issues to illuminate the tensions. For more, *see generally* Michael Malinowski, *Choosing The Genetic Makeup Of Our Children: Our Eugenics Past—Present, and Future?*, 36 CONN. L. REV. 125 (2003); John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469 (2011); Lars Noah, *Assisted Reproductive Technologies and the Pitfalls of Unregulated Biomedical Innovation*, 55 FLA. L. REV. 603 (2003); Debora Pergament, *What Does Choice Really Mean?: Prenatal Testing, Disability, and Special Education Without Illusions*, 23 HEALTH MATRIX 55 (2013); Jessica Anne Schlee, *Genetic Testing: Technology That Is Changing The Adoption Process*, 18 N.Y.L. SCH. J. HUM. RTS. 133 (2001); Ben Shaffer, *The Right To Life, The Convention On The Rights Of Persons With Disabilities, and Abortion*, 28 PENN. ST. INT’L L. REV. 265 (2009); Jeremy Waldron, *How Law Protects Dignity*, C.L.J. 2012, 71(1), 200-222 (2016); Jeremy Waldron, *Two-Way Translation: The Ethics of Engaging With Religious Contributions In Public Deliberation*, 63 MERCER L. REV. 845 (2012); Janet Dolgin, *The Ideological Context Of The Disability Rights Critique: Where Modernity And Tradition Meet*, 30 FLA. ST. U. L. REV. 343 (2003).

237. Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, Special Supplement, HASTINGS CTR. REP. Sept.-Oct. 1999, S1-S2

238. Rosemarie Garland-Thompson, *Integrating Disability, Transforming Feminist Theory*, 14 NAT’L WOMEN’S STUD. ASS’N 1, 16 (2002).

239. *See infra* Section IV.C.

240. SAMUEL BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 103 (Yale U. Press 2009).

241. Robertson, *supra* note 123, at 453.

The numbers bear this out. For example, in the United States, “an estimated 67 percent of fetuses with prenatally diagnosed Down syndrome are aborted.”<sup>242</sup> Parents facing the choice may “feel a sense of loss because they no longer dream that their child will get married, go to college or start a family of their own one day — in other words, that they will not meet the conventional expectations for the perfect middle-class life.”<sup>243</sup> This is despite evidence that many people with Down syndrome do go on to accomplish just those things.<sup>244</sup>

On the other hand, perhaps inquiry into the reasons behind *any* termination of pregnancy is disruptive to the right of privacy held by pregnant people.<sup>245</sup> The threat of anti-choice legislation is a real threat related to subordination on the basis of gender, and an anti-eliminationism perspective in one category should not be used to support subordination.

Nevertheless, the anti-eliminationist concern seems to be different here than in the assisted-suicide case. For example, it is possible that any forces of coercion and misinformation could be more readily corrected here. In the case of suicide, as discussed *infra*, it is one’s own lived experience of, for example, discrimination and stigma or loss of autonomy, that may effectively coerce someone into taking their own life.<sup>246</sup> Here, that is not necessarily the case. Although the parent decision-maker in question may or may not have disabilities themselves, it may be that more accurate information about the quality of life for a child with a particular disability is what is needed. If the critique of prenatal testing and selective abortion is based on legacy problems of stigma and misinformation, then a re-focusing on, for example, the ways in which children with disabilities “can participate in the life of family, school, and community” could potentially remedy those concerns.<sup>247</sup>

A proposal for more accurate information about the lives of children with disabilities would not be out of line with current abortion jurisprudence. *Planned Parenthood v. Casey*, for example, recognized that states may take steps “to ensure that choice is thoughtful and informed” and may “enact laws to provide a reasonable framework for a woman to make a decision that has such a profound

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242. Chris Kaposy, Opinion, *The Ethical Case for Having a Baby With Down Syndrome*, N.Y. TIMES, (Apr. 16, 2018).

243. *Id.*

244. See *Postsecondary Education, NAT’L DOWN SYNDROME SOC’Y*, <http://www.ndss.org/advocate/ndss-legislative-agenda/education/postsecondary-education/> (last visited April 12, 2019).

245. *Roe v. Wade*, for example, was decided on privacy grounds – that a constitutional right to privacy prevents “government intrusion” (or, perhaps, inquiry) into the decision of whether to bear a child. *Roe v. Wade*, 410 U.S. 113 (1973).

246. See *infra* Section IV.C. (discussing physician-assisted suicide).

247. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 335 (2003).

and lasting meaning.”<sup>248</sup> However, if this argument sounds similar to the proposals for giving ‘more information’ to women seeking abortions, which may in reality be attempts to limit abortion rights, that is of concern to anyone who does not seek to eliminate or restrict abortion rights.<sup>249</sup> Furthermore, while abortions on the basis of potential disability might impact the lives of poor people with disabilities more,<sup>250</sup> restrictions on abortion access impact poor women more frequently.<sup>251</sup> While an anti-eliminationism perspective need not necessarily be in conflict with abortion rights, Samuel Bagenstos identifies that the disability rights critique could “serve as a model for those who wish to defend ever more stringent abortion regulations.”<sup>252</sup> This Article has identified these tensions, but a resolution that is satisfactory to both abortion rights and disability rights may be more elusive.

The proposal for more information is also consistent with the guidelines of the National Society of Genetic Counselors.<sup>253</sup> The Society has specifically issued guidelines for “communicating a prenatal or postnatal diagnosis of Down syndrome,” recommending practices such as delivering a diagnosis in person; allowing enough time for questions and planning a follow-up conversation; provision of accurate and up-to-date information in a “balanced perspective, including both positive aspects and challenges related to Down syndrome”; providing the information in a sensitive and caring manner; avoiding value judgements such that the information is “bad news”; avoiding outdated or offensive terminology, including using person-centric language; and provision of outside resources.<sup>254</sup>

Despite these guidelines, some parents of children with Down syndrome report a much different experience with their doctors.<sup>255</sup> A study of parents reporting their experiences in learning such diagnoses found that the parents had “negative experiences with medical professionals during the diagnosis process.”<sup>256</sup> The study identified the “importance of these early experiences for parents of children with Down syndrome and emphasize[d] providing effective

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248. *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 872-73 (1992).

249. See, e.g., Gillian E. Metzger, Note, *Unburdening the Undue Burden Standard: Orienting Casey in Constitutional Jurisprudence*, 94 COLUM. L. REV. 2025, 2082-84 (1994).

250. See Robertson, *supra* note 124, at 423 (arguing that prenatal trait selection may discriminate against women and people with disabilities).

251. Sylvia A. Law, *Abortion Compromise – Inevitable and Impossible*, 1992 U. ILL. L. REV. 921, 931, 939, 941 (1992).

252. Bagenstos, *supra* note 240, at 105.

253. PRACTICE GUIDELINES FOR COMMUNICATING A PRENATAL OR POSTNATAL DIAGNOSIS OF DOWN SYNDROME, NAT’L SOC’Y OF GENETIC COUNSELORS (2011) ().

254. *Id.*

255. Briana S. Nelson Goff et. al., *Receiving the Initial Down Syndrome Diagnosis: A Comparison of Prenatal and Postnatal Parent Group Experiences*, 51 INTELL. DEVELOPMENTAL DISABILITIES 446 (2013).

256. *Id.*

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education, resources, and practical information from reliable sources.”<sup>257</sup> At least some of the concerns of disability rights activists in this area could be ameliorated by more education, training, and information on all sides.<sup>258</sup>

#### CONCLUSION

Because anti-subordination perspectives are typically advanced in order to help solve problems related to race, and to an extent gender, they are not sufficiently developed for use in the disability context. While disability shares many features with other marginalized groups, there are also different complexities that are unique. This paper has identified one such complexity, namely that autonomy comes into conflict with other values for people with disabilities in ways that it does not for other groups. Here is where a central problem for people with disabilities is left out of disability law theory. Autonomy, in the self-ownership sense, is not necessarily in conflict with anti-subordination for most groups, but it *is* in such conflict with disability. And, anti-eliminationism has now been identified as a uniquely disability-related concern.

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257. *Id.*

258. *Id.*